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Empirical Articles

Patients' Perspectives About the Design of a Mobile Application for Psychotic Disorders

Perspetivas dos pacientes sobre o design de uma aplicação móvel para perturbações psicóticas

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Abstract

Aim: Based on the design of applications for psychotic disorders illness self-management, this study aimed to understand patients' patterns of technology usage, as well as their expectations and requirements concerning the design of an app for rehabilitation and illness management purposes. It also aimed to identify guidelines for mobile application development for this population.
Method: After a literature review, a questionnaire was developed, focused on behaviours and opinions about technology usage. It was applied, through a cross-sectional study, to a sample of 102 users of mental health services with psychotic disorders (62% men; with ages between 22 and 66 years old).
Results: Nearly 59% of the participants were willing to download an app for illness self-management, and 51% evaluated as essential the self-management of their mental health condition. However, correlation analysis revealed that the more years with mental illness, the less importance is given to an app for this purpose.
Conclusion: The use of mobile technologies seems to the have potential to empower individuals with mental health problems, especially younger ones and those in early disease stages. Concerns about privacy/security should be considered, as well as simple screening designs and texts. The results also reveal the importance of user participatory design.

Keywords: mobile technologies, patients' perspectives, psychotic disorders, user participatory design, app development

Resumo

Objetivo: Baseado no desenho de aplicações para autogestão da doença face a perturbações psicóticas, este estudo teve como objetivo conhecer os padrões de uso de tecnologia dos pacientes, bem como suas expectativas e requisitos quanto ao desenho de aplicações para fins de reabilitação e gestão da doença. Também visou identificar diretrizes para o desenvolvimento de aplicações móveis para essa população.
Método: Após uma revisão da literatura, foi desenvolvido um questionário, focado em comportamentos e opiniões sobre o uso da tecnologia. Foi aplicado, através de estudo transversal, a uma amostra de 102 utilizadores de serviços de saúde mental com perturbações psicóticas (62% homens; com idades entre 22 e 66 anos).
Resultados: Quase 59% dos participantes estavam dispostos a descarregar uma aplicação para autogestão da doença, e 51% avaliaram como essencial a auto-gestão da sua condição de saúde mental. No entanto, a análise de correlação revelou que quanto mais anos de doença mental, menos importância era dada a uma aplicação para esse fim.
Conclusão: O uso de tecnologias móveis parece ter potencial para capacitar indivíduos com problemas de saúde mental, principalmente os mais jovens e os que estão em estádios iniciais da doença. Preocupações sobre privacidade/segurança devem ser consideradas, assim como desenhos simples de diagnóstico e textos. Os resultados também revelam a importância do desenho participativo do utilizador.

Palavras-Chave: tecnologias móveis, perspetivas dos pacientes, perturbações psicóticas, desenho participativo do utilizador, desenvolvimento de aplicações

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Mental health problems are a growing global concern according to the World Mental Health Survey Initiative (Kessler et al., 2009). In Europe, psychotic disorders in particular have a prevalence of 1.2% (Dominguez, Wichers, Lieb, Wittchen, & van Os, 2011) and the costs of its management amounted to €93.9 billion in 2010 (Olesen, Gustavsson, Svensson, Wittchen, & Jönsson, 2012). These costs are particularly high due to specific characteristics of the disease such as early onset, frequently chronic course, early retirement, recurrent readmissions to hospital, and high rate of disability.

Although mental health is considered a public health priority, there is a clear inadequacy and insufficiency of existing services to the needs of people with mental health problems. Most patients live with their families, in a complicated socio-economic panorama, with poor access to information and other resources which generally elicit a low level of autonomy in several life contexts (Shah, Wadoo, & Latoo, 2010). The Mental Health Action Plan for 2013-2020 (World Health Organization [WHO], 2013) recommend a set of guidelines coherent with a recovery paradigm, emphasizing the importance of considering patients' choices and options, thus promoting their empowerment, self-determination, and active participation in all aspects of their lives and, therefore, of their recovery. These guidelines established the need to promote an integrated approach, focusing not only on patients and their needs and decisions, but also appeal to their involvement in illness management. Self-management refers to the patient's ability, together with family, community, and health professionals, to manage symptoms, treatments, changes in lifestyle, as well as psychological, cultural and spiritual consequences of health condition (Richard & Shea, 2011; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015).

Illness self-management programs are based on the self-efficacy concept (Lorig & Holman, 2003; Sterling, Silke, Tucker, Fricks, & Druss, 2010) and aim to: 1) enhance engagement in activities that promote health; 2) monitor and manage symptoms and signs of disease; 3) manage the disease's impact on functionality; 4) promote informed decisions; 5) ameliorate the adherence to medication; and 6) ameliorate the collaboration with professionals to choose the best possible health care. During the last decade, the concept of self-management gained ground in the mental health context and, consequently, new strategies emerged in this field (Lurie, 2012; Sterling et al., 2010), being precisely one of them the use of technology.

Technology, in general, has the potential to improve quality of mental health services (Ben-Zeev, 2012) and can play an important role in psychological interventions aimed at fostering positive emotions, promoting engagement in empowerment and self-actualization experiences, and supporting connectedness between individuals and communities (Riva, Villani, Cipresso, & Gaggioli, 2016). However, few scientific evidence and recommendations are given to its incorporation into services (Ben-Zeev, 2012). Nevertheless, technology-based interven-

tions are emerging and eliciting the attention of researchers and clinicians (Ben-Zeev, 2014). Several interventions have been recently developed, namely psychotherapeutic interventions based on the Internet (Alvarez-Jimenez et al., 2013; Proudfoot et al., 2007; Rotondi et al., 2010), SMS to support psychiatric care (Bauer et al., 2003; Granholm et al., 2012; Sims et al., 2012), treatment applications via phone and video conferencing (Mohr et al., 2012; Nelson et al., 2003), virtual paradigms for skills training (Freeman, 2008; McLay et al., 2011) and applications that promote autonomy of individuals with mental illness (Ben-Zeev, 2014; Burns et al., 2011; Rizvi et al., 2011). Although more research is needed, some interventions showed similar effectiveness to traditional models, as suggested by some studies: 1) in patients with depression, cognitive behavioural therapy (CBT) using the phone, when compared with face-to-face, demonstrated comparable improvement at posttreatment (Mohr et al., 2012); and 2) comparing CBT delivered through health technologies and therapist-administered CBT, a study revealed no significant differences regarding efficacy, on patients with obsessive-compulsive disorder symptoms (Dèttore, Pozza, & Andersson, 2015).

Regarding mobile applications, recent research demonstrated that its development must be done according to the needs, features and preferences of their final users, in order to develop a tool that will, more likely, be used successfully (Ben-Zeev, 2014), and that the users' experience to have the same importance as the expertise of professionals (Ornelas, Aguiar, Sacchetto, & Jorge-Monteiro, 2012). Thus, user participatory design aims to empower patients, allowing a transition from a passive role where the user is the receiver of care services to an active role. This approach involves users throughout the development process, assuring that technology functionalities are easy to operate and are valued by them (Maguire, 2001). As a principle of mental health care policy, users' involvement is crucial to ensure that services are provided according to patients' needs and enhancing patients' control over their health care. Thus, professionals cannot decide on behalf of their patients without involving them in the process given that users' experience is different from professionals' expertise (Petersen, Hounsgaard, Borg, & Nielsen, 2012).

However, some mental health practitioners are concerned about the ability and willingness of people with psychotic disorders to receive this type of intervention and are apprehensive that positive symptoms such as hallucinations and deliriums, thought disorganization, and cognitive deficits may limit the feasibility of mobile health interventions (Firth & Torous, 2015). In fact, there is a lack of guidelines to develop such technologies for people with psychotic disorders with lower technology literacy (Rotondi et al., 2007) because, usually, self-reported technology skills are higher than demonstrated in task analyses. There are also a few implications for making these tools' usage more reasonable and acceptable for people with severe mental illness, such as having no costs, giving simple instructions to navigate, adequate font size, specific buttons and links, etc. (Black, Serowik, Schensul, Bowen, & Rosen, 2013).

Nowadays, more patients own smartphones and are interested to use them to monitor their health (Torous, Chan, et al., 2014; Torous, Friedman, & Keshavan, 2014). According to Ben-Zeev and colleagues (2013) advanced technologies can support self-management of mental illnesses, but to be feasible they need to be designed addressing real requirements and specific preferences of their final user.

Based on our activity as mental health professionals working with patients with psychotic disorders, we were included on a team whose work aims to develop a mobile application for the rehabilitation and illness management for these patients. In the first stage, and following similar procedures of Torous, Friedman, and Keshavan (2014) and the user participatory design previously referred, this study aims to know patients' patterns of tech-

nologies usage, and their expectations and requirements considering the design of an app for rehabilitation and illness management purposes. Additionally, the study tries to identify issues related to guidelines for mobile application development for this population.

Method

Participants

The sample consisted of 102 users of mental health services with psychotic disorders (62% men; with ages between 22 and 66 years old: M_{age} = 42.4 years, *SD* = 9.6) that participated in this study (Table 1). All participants were diagnosed with a psychotic disorder and were in rehabilitation. In average they were ill for 17.6 years (*SD* = 9.8).

Table 1

Sample Characteristics

Characteristic	Frequency	Percentage
Education Level		
No education	3	2.94
Until 4 years	11	10.78
Basic	41	40.20
Secondary	39	38.24
Graduated or more	8	7.84
Employment Status		
Student	3	2.94
Retired	54	52.94
Employed	3	2.94
Unemployed	42	41.18
Residence location		
Big city	65	63.73
Small city	37	36.27

Note. Big city has more than 200.000 inhabitants.

Materials and Procedure

A literature review was done on EBSCO, Medline and PsychInfo databases, searching papers about research or developments in mental health and mobile technologies published since 2000. Descriptors (text words) were: smartphone; mobile phone; mobile device*; mobile technolog*; mhealth; mobile app; crossed with schizo*, psychotic disorder*, psychosis, voices, and hallucinations. We identified 47 papers, which discussed the use of mobile technologies on health, user groups (health professionals and patients), advantages and disadvantages, clinical applications, and user self-determination. We also analysed mobile phone consumer surveys.

Using these topics, an online questionnaire was developed to assess patients' interest to use smartphones to support their rehabilitation process and to know users' expectations and requirements considering mobile applications design. The questionnaire was structured in three groups[i]. The first was about sociodemographic data where respondents were asked to provide information such as gender, age, city of residence, employment sta-

tus, years with mental illness, and education level. These social determinants and sociodemographic variables are important in order to analyse electronic device use and interest in mobile technologies according. The second group explored participants' technology usage patterns, and how often in the last month they used certain equipment (mobile phone, computer, console, ...), which activities they conducted in the mobile phone and in which contexts. We used a Likert type scale (ranging from 1 = *never* to 5 = *almost always*). Questions about internet use and about phone's capacity to download applications were also presented, as well as the perception level of how difficult the mobile phone use was (ranging from 1 = *very easy* to 5 = *very difficult*). This group aims to know if the sample has digital literacy, i.e., their ability to use information and communication technologies to find, evaluate, create, and communicate information, even if they do not have or use a mobile phone. Thus, being at ease in the use of more generic technologies, they can have more ease in using a smartphone hereafter. The third group aimed to know participants' opinion about the development of a mobile application to support their mental illness' management. We questioned whether the participant would download an application for this purpose and the frequency of its possible usage. We also included open questions about their motivation to use this application and what could hinder its use. Participants were also asked to rate the importance some requirements' importance related with the application development and its features (ranging from 1 = *not important* at all to 5 = *very important*). Finally, we asked about what information patients would like to share with their professional and at what times, using multiple-choice questions. This kind of information would be very useful when designing and implementing a mobile application for people with psychotic disorders. As initial information of the questionnaire, it was explained that: "The use of Information and Communication Technologies (ICT) in the provision of health care has become a widespread significant strategy for increasing accessibility and complementarity to face-to-face care. We would like to know your opinion about developing an app for support in managing their mental illness". Since the questionnaire assessed mainly behaviours frequency, psychometric properties were not analysed.

An initial pilot study to evaluate if they understood the questions as expected and to obtain recommendations for questionnaire improvement was completed by five patients. After this procedure some words were changed, and it was added a "other" option due to the fact that some of the respondents did not found their answer within the given options. Since the study population is difficult to access, we only included five people in the pilot. However, there was a thoughtful selection of these patients, as we tried to present different characteristics regarding the institutions of origin, use of technology, age, and other variables. We asked professionals from different institutions to indicate several users following these requirements and five were randomly invited to participate.

After this pilot study, an email was sent to several rehabilitation services in Portugal, especially FNERDM (national organization that gathers 21 mental health institutions) and São João Hospital Psychiatry Service, introducing the study with a link to the questionnaire posted online using Google Docs. We asked these institutions (with whom the authors regularly collaborate) to send to their patients the questionnaire inviting them to participate. Thus, the authors did not directly contact the patients. In addition, due to the vulnerable nature of this population it was requested an ethical opinion, having the study been approved by São João Hospital Ethics Committee and other organizations own ethics committees' that introduced the study to its users. The survey was made available for eight weeks between the months of September and October of 2015 and took an average of 25 minutes to be completed.

Results

Regarding patients' technologies usage patterns (Table 2), the equipment used more often by participants in the last month was the mobile phone, followed by desktop computers and laptops. Among the 77.5% of respondents that owned a mobile phone, we verified that 34.3% were able to access the Internet and use the mobile phone also to make phone calls, set alarms for medication/appointments, send messages, search for information, see their e-mails and play games. Only 27.5% reported having some difficulty using a mobile phone. Concerning internet use, 57.8% used internet in the last month and the places where they accessed it more frequently were at home and social/health institutions, mainly using laptops or desktop computers. The 29.2% patients that used mobile applications reported that the most frequent purposes are related to games or other type of entertainment, music, and photography. In total, 58.8% of respondents reported that they would download an application for mental illness self-management.

Table 2

Usage Pattern of Information and Communication Technologies

Usage Pattern	Frequency	Percentage
Most used equipment last month		
Mobile phone	69	67.6
Desktop computers	27	26.5
Laptop	27	26.5
Owned a mobile phone		
Yes	79	77.5
No	23	22.5
Mobile phone with internet access		
Yes	35	34.3
No	67	65.7
Location of internet access		
Home	31	30.4
Health/Social institutions	10	10.0
Activities using mobile phone (many times or almost always)		
Calls	38	37.2
SMS	18	17.6
Social networks	11	10.8
Emails	13	12.7
Music	28	27.5
Set alarms	26	25.5

Concerning the participants' expectations to the development of a mental health mobile application (Table 3), they identified features associated with autonomy as being the most important to be included in the mobile application, emphasizing: symptom monitoring, providing information about the disease and its treatment, the ability to record daily moods, stress management and strategies to promote relaxation, reminders for appointments and medication adherence, and being able to track treatment progression (Table 3).

Table 3

Importance Given to Several Aspects and Requirements to Develop an App for Psychotic Disorders

	Not Important		A Bit Important		Important		Very Important		Indispensable	
Aspect / Requirement	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Monitor symptoms	26	25.5	10	9.8	27	26.5	27	26.5	12	11.8
Provide information	29	28.4	3	2.9	33	32.4	25	24.5	12	11.8
Record daily moods	29	28.4	6	5.9	31	30.4	27	26.5	9	8.8
Stress management	29	28.4	7	6.9	31	30.4	23	22.5	12	11.8
Meds/appointments	32	31.4	7	6.9	28	27.5	25	24.5	10	9.8
Track progress	27	26.5	7	6.9	33	32.4	23	22.5	12	11.8
Being interactive	31	30.4	8	7.8	29	28.4	26	25.5	8	7.8
Answer a need	27	26.5	8	7.8	31	30.4	25	24.5	11	10.8
Being private	39	38.2	11	10.8	24	23.5	18	16.7	10	9.8
Being safe	42	41.2	15	14.7	22	21.6	18	17.6	5	4.9
Do not need internet	31	30.4	5	4.9	17	16.7	24	23.5	25	24.5

Aspects such as responding to a specific need, being safe and private, being interactive, and not depending on the internet were the most important factors rated by participants to consider for application development according to respondents (Table 4). Several characteristics were pointed out in an open question as facilitators of application use such as being free, easy to access and use (simple screen, short sentences, few steps to perform an action), and being effective in improving the management of their health condition. On the other hand, the barriers mentioned were the user being in the acute phase of the disease, being paid, requiring a lot of cognitive effort, and not being intuitive to use. These are guidelines that should be taken into account in future app development.

Table 4

Importance Given to Several Aspects and Requirements to Develop an App for Psychotic Disorders

Aspects regarding the app use	***M***	***SD***
Being interactive	2.73	1.344
Answer a need	2.85	1.345
Allow the use of a pin or password	2.50	1.405
Being private	2.33	1.417
Being safe	3.07	1.581
Do not need internet	2.30	1.303
Requirement for an app for illness self-management	***M***	***SD***
Monitor symptoms	2.89	1.364
Notifications for meds/appointments	2.75	1.384
Direct line with professionals	2.88	1.374
Provide information about illness/ treatment	2.81	1.340
Record daily moods	2.53	1.287
Stress management/ relaxation	2.82	1.375
Track progress	2.86	1.350

Specifically, regarding the medication adherence, most participants would like to receive notifications once a day (34.3%) or more than once a day (23.5%), and 61.8% said that these should preferably be received in the morning. Participants had very different perspectives regarding to the information they would like to share with significant others (informal and formal carers). In total, 31.4% of participants indicated they would like their formal carers, such as psychiatrists, to receive a weekly or monthly report; 37.3% indicated they only would like to share information when a record is considered out of normal parameter. They were willing to share usage data, progress on modules, response to mood records, journal entries, goals, and achievements. Also, 25.5% said they would not share information with their clinicians.

The importance given to self-managing their mental health condition was high: 51% said that it was essential, 25.5% very important, and 16.7% important. The importance given to the use of an application for supporting illness self-management was also high: 34.3% referred it is essential, 19.6% very important, and 13.7% important. Finally, Pearson correlation analysis showed several significant correlations between variables such as difficulty in using mobile phone, age, years with mental illness, the importance given to illness self-management, and importance given to a mobile application for illness self-management (Table 5).

Table 5

Pearson Correlations Between Some Variables

Variable	Age	Years with illness	Difficulty use	Importance autonomy
Years with illness	.522**			
Difficulty use	.252*	.209*		
Importance autonomy	.045	-.021	-.317**	
Importance application	-.141	-.244*	-.446**	.530**

*$p < .05$. **$p < .01$.

Discussion

Regarding technology usage, results revealed that mobile phones and computers are the most commonly used equipment by our participants with psychotic disorders. The majority of participants were already using mobile technologies and many are open to self-managing their illness with an application, results that are similar to other studies (Ben-Zeev et al., 2013; Whitehead & Seaton, 2016). Only 23% of the participants did not have a mobile phone, a relatively low number. Regarding patients' smartphone ownership in Portugal (34%), the number is almost half of global mobile phone owners residing in the country (59%), according to Marktest' Telecommunications Barometer (2015). The percentage is below the average in USA but higher than Europe. In 2014, 64% of American adults owned a smartphone (Pew Research Center, 2015) and, in Europe, the smartphone penetration was 25% (eMarketer, 2014). Based on prior research (Depp, Harmell, Vahia, & Mausbach, 2016), we expected that patients with psychotic disorders would have a lower prevalence of mobile phones ownership than people without a psychiatric diagnosis, especially the older patients. For younger patients the use of mobile applications seems to be a pertinent intervention, while for older people initial digital literacy courses may be required. For older patients and patients who have lived more years with the disease the ownership and willingness to use a mobile phone to manage their illness was lower, as initial anticipated. This could be due to some traditional services culture that do not yet promote self-determination and empowerment and block the patients' right to make their own decisions about treatment and about their recovery path. These results are

important as they suggest that patients are receptive to mobile technologies, which is a growing area in the health field, due to its low cost and ubiquity (East & Havard, 2015).

Although we did not evaluate the socio-economic condition in the questionnaire, we considered the responses regarding situation towards work enlightening, since 94% of participants were retired or unemployed. This shows us that low-income situations or dependence on other people such as families is, in fact, a reality in this sample. Although mobile phones use is spreading due to declining prices, we acknowledge that the lack of resources can indeed be an unfavourable factor to access these kinds of interventions. Moreover, our sample is characterized by people with a reasonable level of education (46% with secondary or higher level of education) which may also explain the higher level of digital literacy and greater willingness to use technology.

There are factors that could contribute to mobile health services adoption such as perceived ease of use and self-efficacy (mobile apps should be easily learned and used) and provide these tools with an appropriate service price, one which would be accepted by potential users. Also, people with psychotic disorders could be positively affected in their acceptance behaviours not only by other mHealth users but also by professionals' perspectives attitudes towards mobile technologies (Sun, Wang, Guo, & Peng, 2013).

Despite the benefits they could offer, better standards and validation practices regarding mental health mobile apps need to be established to ensure proper use and integration of these tools into practice. Concerns about privacy and security should also be considered, since patient information must be secure in case the smartphone is lost or stolen. Few steps to perform actions, memory aids, simple screen design and short sentences minimizing abstract thinking are crucial to overcome possible cognitive issues of this population. A recent review (Bakker, Kazantzis, Rickwood, & Rickard, 2016) pointed out sixteen recommendations for mental health smartphone apps, such as: cognitive behavioural therapy based interventions, automated tailoring, recommend activities, especially nontechnology-based ones (behavioural activation), or links to crisis support services. Experimental trials to establish efficacy were also mentioned.

The study has some limitations: we did not collect data from patients that did not attend a rehabilitation service, because it would be more difficult to reach these people; we did not include questions about economic condition but most participants were retired or unemployed which can be reflected in relatively low incomes, as mentioned before; the sample is not representative, but composed by participants who voluntarily accepted to collaborate on the study, therefore, it does not allow to gather scientific evidence that might sustain further decisions in this area. Nevertheless, it can be regarded as a significant contribution to collect information about this emerging field. Future research should consider users' perspectives to design an application that could meet their needs and expectations.

Self-management strategies are emerging due to rising levels in chronic diseases. The recovery model allows patients to take control of their lives and make health choices in a more informed way which is the aim of these technologies (Sterling et al., 2010; Zou et al., 2013). A partnership between clinicians and users concerning mobile applications use as part of a shared decision-making process could benefit people with psychotic disorders recovery. Thus, mobile applications could take an important role in supporting illness self-management as long as developers follow a comprehensive user participatory development process.

Notes

i) The questionnaire can be available by asking the authors.

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Competing Interests

The authors have declared that no competing interests exist.

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